The perfection of vulnerable lives. Genetic modification and disability

La perfección de las vidas vulnerables. Modificación genética y discapacidad

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Abstract

The theorists that defend gene editing techniques without any conservatism argue that they will increase our capabilities and will also avoid unnecessary pain and some types of human suffering. Transhumanist authors such as Nick Bostrom, Natasha Vita-More and Max More not only underestimate the risks of using biotechnology –such as the CRISPR-CAS9 technique– they also assume that living a full human life is directly related to the full enjoyment of our physical and intellectual abilities dismissing some kinds of disabilities. However, disability theorists insist that human limitations should not be seen through the lens of misfortune or in a tragic way; on the contrary, they argue that it is possible to live practically from functional diversity (or disability). Therefore, in this

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article we will try to test both assumptions based on the idea of disability and, in that way, show if necessarily happiness depends strongly on the functionality of the human body.

Keywords: disability, transhumanism, CRISPR-CAS9, genetic engineering, suffering.

Introduction

Based on the scientific contribution of biochemists Jennifer Doudna and Emmanuelle Charpentier, the genetic modification of any living being is today a tangible reality. They fulfilled the dream of many scientists by developing a technique called CRISPR-CAS9, capable of cutting out and inserting the genes of any living being into another, including, of course, genetic information from humans.[1] With such a technique it is now possible to eradicate diseases, redesign damaged ecosystems and, in general, to intervene in the original design of the body with the pretense of correcting «errors» in the DNA, under the assumption of avoiding unnecessary and random suffering for people suffering from diseases such as cancer, cystic fibrosis, sickle cell anemia, malaria or HIV (2). To speak of such an achievement in the scientific world would seem, at first glance, to be a subject of science fiction; however, it is already in the application of contemporary biomedicine (3).

However, the discovery of this technique would not necessarily be a problem *per se*; for some biochemists and geneticists, having developed this tool is in fact an achievement that will benefit the survival of flora and fauna for human consumption. Although this represents important problems of another kind (4, 5), they celebrate that in recent years the maize genome has been edited to adapt its cultivation and increase its survival in all environments (2). In the case of animals, goats and pigs have been modified to

have greater muscle mass; this would mean that fewer animals can provide more meat for human consumption and this is shown to be a strong advantage (2).

These interventions, with the use of CRISPR-CAS9 technology, arise from the need to improve the conditions of man and achieving this is one of its objectives. Theoretically, it would be a matter of preventing famines, improving the environmental conditions that have made impossible the cultivation of several species or the reduction of breeding animals without affecting the same meat production, but reducing pollution considerably. However –this is mentioned by Doudna herself–, the thin line that exists between experimentation and the crossing of genes of living beings is extremely blurred. In recent years, says Doudna, attempts have been made to «humanize» the DNA of pigs in the hope that one day their organs can be used for transplantation into humans (2). As a final feature of this powerful tool, the possibility of editing mutated genes that cause severe diseases would open the door to the treatment of genetic therapies with the aim of completely eradicating the genes that cause the death of millions of people, not only today, but also in future generations.

So, on the one hand, we seem to be faced with a tool that seems to give us all the answers and solutions to the mystery of life: for hundreds of years man has been trying to decipher the weakness of human nature in the presence of disease and the cause of death. This feeds the illusion that today we have the opportunity to remove several of the causes of suffering and pain that have tormented man so much and that there is a sure way to improve the quality of human lives and, in that sense, to perfect human nature. On the other hand, this perspective leaves aside the socio-cultural and economic dimensions that mediate health care or the passage from illness to health. Dimensions that also cause psychological disorders and moral damage and whose avoidance biases and reduces considerations of human life. Moreover, possessing this genetic key opens a pandora's box of which we know almost nothing.

Without prior ethical and socio-political analysis, it is not clear what would consist in improving human nature or what the consequences of the modifications would be, in order to lessen the suffering of people (2). At first sight, since science allows us to master natural laws, genetic modification could be considered as the next step for the emancipation of human beings, in the sense of freeing them from the deficiencies, limitations, deterioration and disability to which they are naturally subjected. To this scientific project, so understood, authors like: Nick Bostrom, Nicholas Agar and Natasha Vita-More –belonging to the current known as transhumanism–, who defend a philosophical project that is characterized by the defense of science as the best tool to reduce the risks of our mortality and improve our human condition by alleviating all kinds of physical suffering (6). In other words, the key of transhumanism, as a philosophical and scientific current, consists in re-contextualizing humanity in technological terms, in order to free us from the prison that our biology implies.

Above all, the emphasis lies on their concern for the *deficiencies* of the human body; in other words, they assert that our nature, being unfinished, implies the arrangement or correction of the physical traits that limit our full development, thus solving the complexity of suffering through technological intervention. Genetic modification is presented, then, as one of the best options for ensuring human welfare and happiness. The latter, assuming that the suppression of pain and the correction of physical deficiencies is equivalent to a full and happy life for all; without taking into account the emerging technological dependencies and differences (e. g., economic and geographic) that could be derived from such technological application. Such a scenario of perfection and total emancipation would be the moment of post-humanism. That is, the human being would reach a point where he would have the capacity to live completely healthy and active, physically and mentally; his mental capacity would be given to the maximum of his possibilities, he

would have total access to his emotions, controlling them in all situations of his life (7).

Transhumanism, says Max More, must be understood as the continuation of the essential ideas of the Enlightenment, since they assume that human rationality, together with science, shapes culture to this day, taking it to the limit of techno-utopianism (7). By taking root in the modern project, transhumanism assumes a separation between the human being and the natural world, which derives in a logic of domination of nature (8), since, by taking Francis Bacon as its main precursor, the scientific method is perfect for obtaining the answers that nature has kept secret. It is even valid to torture it in order to improve the human condition (9). The so-called transhumanists are going to take up again the emphasis on progress and, as in modernity, they will take as a personal task the creation of better future scenarios. They will not have to wait for supernatural forces to help them, but they will be masters of the technological tools, and therefore, faith will be reduced to human creativity (7). Based on the belief that human beings possess such an extraordinary rationality, capable of having control over the world, that they need nothing but themselves, transhumanism declares itself to be a humanistic and secular current where there is no God. It finds all answers in science and human reason.

However, we believe that there is a problem with the progressive and scientific vision of modernity and the subsequent transhumant ideal that we are going to point out in this article; it seems to us that as people accept as a premise the admiration for modern progress and seek to dominate with disproportionate eagerness, by becoming masters and lords of nature –precisely because their logic wishes to break with any limitation–, they are at the same time conducive to a series of important negative consequences. As early as the end of 1940, various thinkers detected some dangers that are worth remembering.[2] For example, Max Horkheimer states that

«the human being, in the process of his emancipation, shares the same destiny as the rest of his world. The domination of nature implies the domination of man» (13, p. 47). In other words, if the human being wants to separate himself from nature in his eagerness to escape his own limitations, he finds himself tied to the same rules of his lordship and subjected even more to domination (14).

Above all, if domination is useful to achieve such needs, every criterion of choice will depend on it, and the Promethean aspiration to remake nature in order to satisfy needs created by society itself becomes increasingly dangerous because the problem does not consist in mechanization, but in the impulse to dominate (15). In this way, it increases the rupture with nature and with its own natural reality. Even if humanity pretends not to be part of the nature it wishes to control, in reality, it cannot escape from that dominion.

In addition to the above paradox, we must point out that the human constitution seems to be intrinsically vulnerable, at least to some extent, and this makes the transhumanist ideal impossible *per se*. Following Eva Kittay, who identifies with the ethics of care, we note that our biological fragility is not surmountable inasmuch as it is also ontological and constitutes the proper way of living humanly (16). However, far from appearing as a tragedy, a problem to be overcome or an obstacle to the happiness and full development of our lives as human beings, fragility and the possibility of illness are a call for the interconnection and interpersonal relationships of care that are precisely what give meaning to human life. The recognition of our vulnerability is precisely the necessary starting point for seeking solutions that will certainly alleviate suffering and resolve human needs. From the perspective of this philosopher, human demands are not to be resolved from immunity and pure prevention of suffering, but from the availability to care and be cared for with special sensitivity to the various personal contexts, disadvantages, socioeconomic problems and political realities, etc., that may influence a complete experience of care (17).

In this sense, the impulse to care should be superimposed on the impulse to dominate.

Kittay, like the other representatives of the ethics of care such as Joan Tronto or Carol Gilligan, prioritizes concrete care relationships beyond universal structures (18), the experience of personal encounter above the scheme of scientific reasoning and plurality of care, as well as care above the universal and utopian solutions of technology. Based on the work of authors such as Kittay, we consider it important to recognize human complexity beyond the strictly functional biological, as transhumanism wants to do. Reflecting on disability and forms of dependency is a good incentive to make visible those limits of the human being that, at the same time, are its possibility of existence.

Human lives seen from the prism of modernity, which is also in the background of the transhumanist posture, appear as superior to the rest of nature due to their functionality and specific capacities (19), since modern philosophy strengthened the ideas, current ideals in today's western societies, of autonomy interpreted as emancipation and that of the progressive development of our capacities, vigor and mastery of the body. The distinctive qualities of the human defended its supremacy over other beings and at the same time justified the idea of progress and aesthetic, functional and physical improvement. This need for linear progress, coupled with the construction of the modern autonomous individual, gradually led to a capacitance discourse, rooted in the medical and scientific discourse, but which also produced a political discourse based on this idealized human model that assumes the need for productivity and economic competitiveness as a basic value.

1. Genetic modification as an emancipatory project

The high point of genetics began in 1966 with the discovery of the universal language of cells: DNA. Moreover, the biologist and pio-

neer of genetic engineering, Robert Sinsheimer, in his speech at the California Institute of Technology, states that with this knowledge, man would come to alter «specifically and consciously his own genes», which is incredible on the one hand, but on the other, it could be equally disastrous (20). And indeed, in 1973, Paul Berg made the combination of genes possible. Five years later, *in vitro* artificial insemination showed how easy it can be to place a fertilized egg in a test tube (21). Thus, the very fact of extracting the beginning of life as an object of experimentation was installed as a watershed of science. Very little time has passed since Sinsheimer's speech and today; however, technology has advanced exponentially. It could be said that the discovery of CRISPR-CAS9 became the turning point of genetics in the 21st century. Not only is the basic structure of living beings known, it is now possible to find the correction of the gene that causes complications such as Alzheimer's, cancer or sickle cell anemia, among many others.

The idea is attractive because it proposes a liberation from the limitations of our nature; it allows us to take control of choosing what we want to «cure» of a person; it promises to eradicate diseases and improve the future social conditions of the human being. Moreover, for its proponents, thanks to genetic engineering, the future looks like the greatest era of well-being in human history (6). As if this were not enough, in the face of the possibility of vanishing these congenital diseases, the opportunity for *enhancement* is also looming. That is, there is the tempting possibility of «producing» people with higher IQs, stronger, more beautiful, with infinite tolerance for pain, and above all, there is the possibility of eliminating what society has pointed out as deficiencies or disabilities (22). As transhumanists argue, if parents could choose the traits of their children, who would want, under this paradigm, to wish that their children were born blind, paralyzed, with Down syndrome, or simply, short, weak and unintelligent? [3]

It is due to these different interventions that the dispute between two sides arises: the transhumanists and the bio-conserva-

tionists (23). We could catalogue in the first ones all those who believe in all kinds of «physical improvement» and even claim that people should be free to transform themselves into radical modes. Some even go so far as to say that genetic modification will become a moral duty (23). This way of thinking reflects the ideas of philosophers such as: Nick Bostrom, Natasha Vita-More, Julian Savulescu, Max More, among others.[4]

The second category includes those who claim that we should not substantially alter human biology (23). Here we find thinkers such as Jürgen Habermas, Hannah Arendt, Michael Sandel, Francis Fukuyama, and even disability theorists such as Fiona Campbell, Elizabeth Barnes and Barbara Arneil. Many authors question the use of genetic engineering in different ways. With great depth and skepticism in the power of science they expose the political and social dangers that can arise from the manipulation and control of natural processes. Of particular concern is the damage to human dignity (24).

However, in this section we will place special emphasis on transhumanist arguments to show how their thinking, being built from the idea of domination of nature developed in modernity, derives into a functional notion of the human being. Above all, to understand the transhumanist project we must be clear that human nature, being an unfinished project, together with the correction of our deficiencies, will be given with the ultimate goal of reaching the stage of an absolute control of nature called post humanism. That is to say, no more illnesses, physical and mental deficiencies, nor more suffering. This will be reflected, mainly, in the thin line between what is considered a medical treatment and what is called an *enhancement* of human capabilities.

Transhumanists blur the boundaries that exist in the arrangement of an incorrect gene, which caused an illness or a disability, and the «enhancements» of a «healthy» subject (9).[5] The separation is so relative in medical terms that even Nick Bostrom will accept that the distinction lies in an instrumental and socially acceptable

criterion; he states that the distinction depends on contingent interventions based on what is considered a «healthy» subject (9). Such a criterion would justify going through a kind of quality control of babies, thanks to which they do not have to come into the world unless they comply with a «certain functionality», since parents would love more strongly a child who is intelligent, beautiful, healthy and happy (9). But what is healthy? Under Bostrom's posture: the aim is that this produced subject –as if it were an artefact made to perfection–, should have an optimal life and without diseases. However, what is not contemplated is that such development starts, *per se*, from a notion of human nature as something that can be mastered and fully controlled by the scientist. This would mean that to produce a being with traits imposed by the socially accepted is equivalent to that person automatically being happy and not suffering.[6] In other words, being socially functional and manufactured according to these parameters would produce greater happiness. Moreover, to modify the genetic line would imply, under Bostrom's thinking, «curing a disease» and at the same time producing perfect beings. For him, even prejudices against people with disabilities would be eliminated:

> The practice of germ-line enhancement might lead to better treatment of people with disabilities, because a general demystification of the genetic contributions to human traits could make it clearer that people with disabilities are not to blame for their disabilities and a decreased incidence of some disabilities could lead to more assistance being available for the remaining affected people to enable them to live full, unrestricted lives through various technological and social supports (9, p. 498).

In that sense, genetic modification would release people with disabilities who possess «defective» genes. In other words, the justification for interventions in biological processes lies in obtaining satisfactory results, since a kind of fullness and no restrictions in the physical and cognitive development of the human being are desired. Such a correction would save us from discrimination and

the existence of subjects who need more help than others on a daily basis. Here we can see the instrumental feature of his posture, since his criterion is based on the gains obtained from the results, on the efficiency and on the savings of the production. The key question would be: if we correct from the beginning of life the genetic faults of the human being and even improve the basic skills, we save the costs and suffering of diseases.[7] Furthermore, reproduction becomes a new type of production, since individuals are manufactured that function correctly under the prevailing social schemes. In this way, the authors say, discrimination and special treatment of people who are different is avoided at its root, denying them existence beforehand (26).

If society dictates that tall, beautiful men have a better chance of being hired by a company and getting a partner than someone who is short and blind, fathers will choose for their children the traits that ensure success. There is statistical evidence that they will be happier under this previous design. However, what if they are all equally tall, beautiful, and smart? Probably the criteria would change, because you want to be the best of all (9). Bostrom has no problem with the transition of criteria as long as they are socially acceptable; however, it is naive and easily dismisses the possible consequences that such a vision could have on society. *Only after a fair comparison of the risks with the likely positive consequences can any conclusion based on a cost-benefit analysis be reached. In the case of germ-line enhancements, the potential gains are enormous* (9, p. 501).

If we look at genetic modification under a cost-benefit model, surely the most efficient, useful and easy thing to do is to make perfect subjects; even more so if the statistics say that the results will help everyone. The radical question, however, which Bostrom does not answer here, is whether this would help build more humane societies.

Along the same lines, Peter Singer argues that the same data from Western countries show that the distinction between therapy and *enhancement* is non-existent. Perhaps, Singer explains, it could

be considered a moral distinction, but in reality, surveys show otherwise. Again, the argument lies in criteria of statistics and success.

> In any case, even if it is possible to distinguish between selection for disabilities and selection for enhancement, it would need further argument to show that this distinction is morally significant. If, as surveys in most developed countries show, at least 85 percent of couples are willing to abort a fetus that has Down's syndrome, most of them will also be willing to abort one with genes that indicate other intellectual limitations, for example genes that correlate with IQ scores below 80. Why not select for at least average IQ? Or, since genetics is only one factor in the determination of IQ, select for genes that make an above average IQ likely, just in case the environmental factors don't work out so well? (27, p. 279)

The surveys largely reflect the preferences and desires of society. Singer's position not only makes explicit the contingency of the criteria and features, but also the infinite changes that can be made. All the characteristics that enter the list of the perfect or imperfect are totally subjective, since they are reduced to the capricious requests that parents want to find in their children. We could think of all those dystopias that have been written; consider them as possibilities of the future and, even so, several transhumanists state that it is obvious and obvious to aspire to have a perfect child and, consequently, healthy and happy. Perchance is it not clear that benefits exceed, by far, costs? And not only economic costs in the sense of implementing public policies or institutions that help sick or disabled people, it is a key saving of human suffering. In other words, it is an economic and happiness calculation. A clear and striking example is found in Iceland in relation to people with Down Syndrome. In the year 2017, the geneticist Kari Stefansson mentioned that Iceland had already –almost completely– *eradicated* Down Syndrome from Icelandic society, since when pregnant women have an ultrasound done, they abort if they see an abnormal chromosome. They even claim that abortion is not a murder, but a

justified anticipation of future suffering that they assume the child and his or her family will have in a necessary way (28).

But, then, keeping in mind the transhumanist logic and its zeal for human progress, in truth: What is the determining criterion they use as the main premise for genetic intervention? What does it denote the intention they have in wanting to genetically modify? We will outline three concrete examples to answer both questions.

Let us begin with the first case in the context of sport. We know that Lance Armstrong was under suspicion for doping in cycling and did not confess to it until after he had won the *Tour de France* seven times. As a consequence, all his trophies were withdrawn. However, it is a known fact that in the world of cyclists practically everyone takes some kind of steroid to endure a whole month pedaling 200 km a day (29). This, coupled with a level of Olympic competitiveness, causes them to demand themselves beyond their natural abilities. In the documentary *Icarus*, Bryan Fogel with the help of the former director of the Moscow Anti-Doping Center, Grigori Rodchenkov, shows that it is impossible not to take steroids but that it is still possible to come out clean in all tests (29). Cycling is only the tip of the iceberg; at the Winter Olympics in Sochi it was revealed that dozens of Russian sportsmen had participated in a state project, to improve their performance during the games. This not only caused several sportsmen to be banned, it also exposed Russian politics, and especially Putin (29).

However, does this mean that sports are becoming a farce? With a higher level of competitiveness, a normal person could never endure that amount of physical demand without an external «help» or *enhancement*. If this is so, is it not easier to «produce» athletes capable of withstanding these demands and save themselves public humiliation? A transhumanist would answer without hesitation that yes, since it is easier and more effective, it is better in every way. On the one hand, it is already known that athletes need outside help to be able to perform. This is a fact. On the other hand, to belong to the best in the world it is not enough that drugs

remain in the body for a very short time, so injections and dependence on these substances becomes, on several occasions, an addiction (15). Manufacturing sportsmen and women is a great solution. Painful interventions are avoided because, in the end, how would you distinguish between modifying an athlete from taking drugs to win? Anyway, they already take something that improves their «natural talents». Both options are presented as an *enhancement*. Besides, we all love winners. We are proud to see medals hung around the necks of our athletes; we are thrilled to watch our favorite team raise the cup of a championship. We believe in success above all else. In that sense, it is much easier to make perfect athletes who are designed to win and to entertain people who are fans. Such a level of competitiveness would lead to greater challenges and greater records. In short, it would be beneficial for many people.

Let us now move on to a second example on the cognitive plane: the use of stimulants. In particular, what is called *enhancement drugs*. What would be the difference between a child who takes a nerve stimulator because he has attention deficit and one who does it to do well on his college test? The use of medications such as Adderall or Ritalin are intended, in principle, to help people who have some degree of attention deficit disorder. They cannot concentrate easily and cannot pay attention for a long period of time, so they must be medicated with a cognitive stimulant (30). That is to say, they require external help to be able to function and perform like the rest of society. However, in recent years, the consumption of this medicine to improve academic performance in the university has become a new black market. Both medications are regulated exclusively for consumption by people who, in effect, have ADHD. However, what was originally a drug to regulate a physical deficiency has crossed the line to become a drug that exponentially increases a person's performance. College students, Silicon Valley engineers, financiers of large stockbrokers, music producers, and athletes get these pills to perform perfectly and get the best results (30). In this

sense, the question is what would distinguish taking an Adderall from having a coffee in the morning to have energy or an ibuprofen to remove a simple pain? Every day we have supplements that increase our performance. We need it for the day to day. The high competitiveness of society, coupled with the projection of professional success, causes a need in the consumption of such drugs. The effects are great: a pill induces hours of high concentration, causes euphoria, suppresses pain and allows performance with large doses of adrenaline. The problem is that the effect passes and, in addition, being an amphetamine, it generates addiction, so in the long run the cost is greater for the person and for the State (30). This example is interesting, because a medical intervention that in principle equalizes the conditions of the subjects who have the deficit, crosses the line and becomes an *enhancement drug* for those who want to win and be the best in everything. And the most striking thing is that it is society itself that demands this level of success and performance (30).

This arouses a positive response in the transhumanists who bet on the manufacture of beings with superior intelligence. Moreover, for a large number of people the transhumanist response does not sound so bad after all. If we assume that intelligence works as instrumental rationality, betting on superintelligence is the best option. Nick Bostrom assures: *By «intelligence» here we mean something like instrumental rationality-skill at prediction, planning, and means-ends reasoning in general* (31, p. 3).

In the end, you want to meet the expectations of success. It's about getting the best job, getting the best grade. All of this, of course, while complying with other social criteria: going to the gym, attending parties, living with the family. While more and more points are added in life, happiness is assured, at least from this transhumanist point of view.

Finally, let's look at an example that seems to be disruptive. In 2002, a deaf couple wanted a sperm donor who was deaf to guarantee their daughter's deafness because, for them, «being deaf is

not a disability, but a cultural identity (32). However, the case caused quite a stir, as who would want their child to be born with a disability? Isn't it supposed to be the other way around? You want to save complications, suffering, physical and cognitive deficiencies for the progeny. Nobody would say anything in the case of extraordinary abilities; that is, intelligence, height, no disabilities. Why? Easy. Because of the key criteria we use to identify what is characteristically human, what defines and specifies people.

Underlying the three examples we chose in this section is the same criterion of functionality. In the case of intelligence and athletes, both illustrate the dilemma: what is the easiest and most efficient? Of course, the production of geniuses and sportsmen is the most useful, because it implies, in the first place, putting the subjects in the same condition of possibility (33). By being modified and predetermined to be good at what they were chosen for, they are all in equal conditions to succeed. Secondly, it shows that we do not know the limit between medical treatment to «repair» a disease and genetic improvement. To what extent should such treatment become an improvement, for something that is socially considered a deficiency? The criterion is pragmatic and also depends on the functioning. The problem, however, is that this criterion of usefulness used by transhumanists assumes the human being as a «thing» with which one can experiment, can be perfected and also discarded without defining on what basis one really decides what is desirable and what is not. Above all, we should think about who decides it? To depend on the functional is not a sufficient criterion because at the same time it depends on the models imposed by society (25).

From the previous examples we can glimpse the intention of the transhumanists; it is not only a question of the model or the instrumental and functional logic they adopt. It reflects a social scheme of calculation and success. The human being is happy when he can cross off a list of demands and criteria with which he complies in an excellent manner. But, when one assumes the hu-

man being under this logic, one must accept all that it implies. If one does not succeed in reaching a goal, it is a defective product. It is not useful, it is something that does not work under the schemes of the socially acceptable.

2. Construction of the man in the modernity and its relation with the «capacitism»

Barbara Arneil has insisted on the problems derived from binary rationality which, based on the assumptions of modern political philosophy, has divided human lives into those who can be full rational citizens and those who cannot be (34). According to the author, modern political philosophy bequeathed to us this opposition between dependent, irrational *versus* autonomous, agency and productive capacity. Locke, Hume and even Rawls emphasized the individual capacities that people could bring to their societies and ignored the influence of the social environment on public health as much as the interaction between the environment, society and the individual health of citizens in the production of integral well-being. Ideas of normality and specifically human rational capacity shaped modern political paradigms:

> If the rational citizen or person at the heart of all these political theories is repeatedly constituted in direct opposition to the disabled other who is defined as less than normal, irrational, outside the usual way of being, only potentially human, and governed by the principle of charity rather than justice, it is clear that to incorporate disability into contemporary political thought is not simply a matter of including the disabled within existing norms or paradigms (34, p. 228).

In clear contrast to this trend of political modernity, Arneil evokes functional diversity as something positive and does so from a non-productivist, non-utilitarian logic. The new narrative he proposes should not be based on autonomy and capacity, but on vulnerabi-

lity and interdependence. To this end, it takes up Kittay's proposal that suggests vulnerability as the nucleus of the new paradigm for thinking about the value of human life. For these authors, the moral value of human lives does not lie in their capacities, their functions, their productivity or their autonomy, but in their vulnerability and their need for care. The virtue of care, which does not necessarily imply direct reciprocity or productive retribution, requires that we be transparent to the concrete needs of the other that is a distinctive moral capacity of people. However, the universality of care and dependency also involves the most dependent, not only those who are able to provide care.[8]

This logic of care, rooted in vulnerability, is opposed both to the logic of domination that we have already discussed at the beginning, and to the logic of «capacitism» that emphasizes the value of productive effort and the efficiency of factual results, utility. This does not mean that Kittay does not consider the pragmatic importance of care, since care also requires effectiveness and efficiency, but this is not the priority, the priority is in the personal encounter with the person who is being cared for.

From this perspective, disability, imperfection and the very human condition of fragility that makes us prone to illness are inevitable. Accepting this as a realistic starting point, however, is not tragic, but represents the condition of possibility for interconnection, conscious interdependence and caring (and even loving) relationships. In Kittay's words:

> The ethics of care emerged as a feminist alternative or supplement to theories of justice found in modern political and moral philosophy. In response to the focus on the individual and the ideals of independence in these theories, an ethics of care emphasizes the relation character of human life, the relational nature of self-conceptions (especially as found in women who, traditionally, have been the primary carers) and the inevitable human dependence and interdependencies too often ignored in theories that begin with adult moral agents pursuing their own conception of the good. An ethics of care takes seriously the labor of care in

> which women traditionally have been engaged. It argues that the values embedded in this labor, for example, the significance of connection, attentiveness and responsiveness to the needs of another, a sense of responsibility and empathetic concern for the well-being of particular or concrete others, are at least as important as justice-based moral conceptions such as rights, impartiality, and autonomy, grounded in reason (17, p. 453).

Recognizing universal vulnerability (although there are variations in origins, types and degrees of vulnerability and dependence from context to context and from person to person), allows us to easily denounce the myth of «capacitism» linked to the modern notion of a rational, autonomous, productive and constantly advancing human being.

Fiona Campbell defines «capacitism» as a series of beliefs and practices that produce a particular type of body standard that is projected as perfect and typical of the species. Thus, disability appears as a diminished form of human being (35). Thus, a generalized way of classifying populations according to degrees of ability, differentiation, denial and non-existence is developed. It is not a question of denying the humanity of any person, but it supposes a hierarchy or prioritization of human lives according to their productive capacities and health conditions (36) that cause negative attitudes towards people with functional diversity, even to the point of humiliation or contempt.

[...] as a conceptual tool, capacitism (ability) transcends the procedures and structures for governing civil society, and is clearly positioned in the area of the genealogies of knowledge. There is not much consensus as to which practices and behaviors constitute capacitism. Nevertheless, we can affirm that a fundamental point of the capacitance view is the belief that the impairment or disability (no matter what «type») is inherently negative and should, if the possibility arises, be improved, cured, or even eliminated (37, p. 2).

We could say that, for Campbell, a harsh criticism of modernity, the myth of capacitism is ultimately rooted in a false belief in the

engine of unlimited productivity and progress. One of the errors is to pose the healthy and capable body as the norm or average. This positioning of the normal, proportional to the interests of the dominant groups, demarcates the existence of certain preferable bodies and others that are disposable. Bodies endowed with certainty, strength, autonomy, and dominance are preferred over the «disabled» body that appears as abnormal, as transgressive, deviant, and undesirable. Disability then becomes a personal or family «tragedy» that must be avoided whenever possible.

In clear opposition to this capacitive discourse that could well be sustained by transhumanists who, like Bostrom or Vita-More, are inclined to favor genetic modification and human improvement under the cover of science, is Elizabeth Barnes. The philosopher asserts that disability is so natural and human that it should not be approached as a problem to be overcome or something to be cured, but rather it should be valued and even celebrated.

Barnes distinguishes between *bad-difference* and *mere-difference* to understand the kind of difference that results from disability in its interaction with the idea of well-being. Accepting disability as a mere difference dismisses the idea that people with disabilities are less well positioned for life than people without disabilities and embraces the possibility that a good life is possible for anyone without relying on intrinsic and indispensable basic capabilities.

Barnes' view of mere difference assumes that the very loss of some assets can open up the possibility of sharing in other assets (even those directly related to living with a disability).

> For example, a defense of the mere-difference view can grant that the ability to her is an intrinsic good. And it is an intrinsic good that Deaf people lack. But here might be other intrinsic good –the unique experience of language had by those whose first language is a signed rather than spoken language–; the experience of music via vibrations, and so on –experienced by Deaf people and not by hearing people–. Deafness can involve the lack of an intrinsic good without being merely the lack of an intrinsic good (26, p. 90).

Barnes' perspective invites us to think that the mere difference of disability does not necessarily imply the reduction of one's overall well-being despite the loss of some specific assets. In other words, disability does not in itself carry an intrinsic cost that results in an automatic loss of well-being, nor is it necessarily connected to the frustration of desires. In fact, Barnes believes that people with disabilities are just as capable of having their wishes frustrated as anyone else, and in some cases, they may even be able to improve their lives from an acquired disability. This, however, does not mean that the disability must be sought or caused, but it does invite us to reflect on therapeutic overkill, the insatiable search for improvement, healing, and immunity.

Valuing disability as part of human diversity across space and time and not considering it a tragedy, a deficit or an abnormality (34) also signifies the value we place on health, the search for perfection, beauty and the increase of our most valuable capacities. Furthermore, it reviews the fundamental values behind our social constructions and our future expectations. In this way, the apparently incontrovertible statements about the expectations of parents, which for transhumanists are based on the possibilities of happiness and success of their children, are put to the test. A clear example can be found in what Kittay said, based on her relationship with her daughter Sesha, who has a severe cognitive disability, with no measure of IQ:

> How do I describe Sesha? In speaking not only about her, but for her, I have already begun by describing her in the negative, as one who cannot speak for herself. Yet this lack is a synecdoche for all that she is unable to do: feed herself, dress herself, walk, talk, read, write, draw, say Mama or Papa. I would have preferred to start by speaking of her capabilities: the hugs and kisses she can give, her boundless enjoyment of the sensuous fell of water, of her abiding and profound appreciation of music. When asked about my daughter, I want to tell people that she is a beautiful, loving, joyful young woman [...] (17, p. 559).

Kittay and Sesha do not suffer necessarily from disability as a transhumanist would believe. On the contrary, according to the author, she and her daughter enjoy and accept the differences with which they live. In any case, it would be a mistake to think that every life, no matter how «perfect» it may be, will be free of suffering.

Here it would be worthwhile to distinguish between pains and suffering, since the former refers to a somatic experience.[9] On the other hand, suffering is existential. The question becomes complicated when transhumanists confuse them and consider them indifferently. Since their objective is to make efficient and eradicate everything that is not pleasant and useful, they then assume that everything is reduced to the biological. When suffering can be approached from the cultural, social, political, psychological. The techniques of improvement, the operations, the implants, have for them the purpose of eradicating pain and suffering under the same mechanisms that reduce human life to its corporal biological aspect (Cartesian *extensive res*). By privileging the biological aspect it is attractive to be able to avoid any type of pain. This type of thinking has led modern societies to experience algophobia and pharmacophilic. The algophobia is the fear, aversion, rejection and intolerance to the pain in anyone of its forms and the pharmacophilic is the attachment to the consumption of analgesics, the disposition to use them in any kind of situation.

However, if we reduce every circumstance to the pleasant or the painful, and above all, if we limit every human dimension to the merely physical, we find ourselves before a society that is not capable of accepting any other form of life that moves away from its hedonistic and utilitarian paradigm. That is why for transhumanists any illness or suffering will be seen as a problem that necessarily requires a practical and efficient solution. In other words, they seem to assume that human existence will be realized through science, which is presented as the panacea for all personal and social difficulties. It will be an awful moment when they realize that the universal cure will never exist.

3. Responses to transhumanist reductionism

We detect an essential flaw in the transhumanist proposals: their vision centered on the biological dimension of the individual that «considers the body as a material reality product of our genetic inheritance» (39, p. 58), forgetting that the production of diseases and disabilities is also gestated through practices and omissions of social, economic and political order. On the other hand, it seems impossible to us to guarantee the immunity and stability of healthy bodies in the face of the uncertainty, change and fragility inherent in human lives. Trying to achieve this through technological intervention and genetic improvement overlooks the fact that the human being is an entity situated in a specific cultural and social context, in whose mechanisms of health conservation and development of capacities mediate processes of care and promotion of psychosocial well-being.

The reality is that there are no human bodies decontextualized to be cared for (from corrective or restorative techniques) or that can be improved and adjusted to a functional ideal that is sociopolitically and culturally neutral and that protects them from suffering from diseases that are equally abstract and neutral. Since:

> The disease is a complex phenomenon that cannot be defined only from the biological point of view, because it derives from an articulated set of cultural and political processes, loaded with social connotations. In other words, diseases are the result of many variables, not only biological, but also environmental, genetic, socio-cultural factors, which come together in the same individual and are manifested in a particular way in each case (40).

The processes of health-disease-life and death are crossed by socio-cultural realities and are not only determined by the genetic conditions of individuals. On the other hand, medical and technoscientific practices are not neutral or perhaps alien to the political, economic and ideological terrain in which they are inserted. Mo-

reover, for several years now, disability has no longer been understood as centered on the body or cognitive functions of individuals but from a social perspective. We explain this in more detail below. For now, we want to emphasize that there are structural conditions that favor the appearance of disabilities as much as of illnesses and diseases. Eradicating them implies addressing socioeconomic inequalities (suffice it to give the example of malnutrition that can cause child malnutrition and death, diabetes, overweight and a series of avoidable comorbidities, all of which are beyond the scope of personal genetic conditioning). In the search for human well-being and happiness, it is necessary to solve the problems caused by the unequal distribution of the risk of acquiring disabilities or the differential distribution of avoidable damage to health and bodily integrity. It is also necessary to promote other extra-biological issues such as promoting the responsibility and agency of the patient, harmonizing psychosocial health and the meaning of life of individuals and groups, addressing geopolitical or territorial inequality to promote the social reproduction of collective health and not only individual, and so on.

The fiction of the existence of dispossessed, asexual bodies that are designed and prepared for a culturally, socially and politically aseptic life overlooks the conceptions of illness that have been proposed from medical sociology, medical anthropology or social epidemiology as much as the idea of disability understood under the social model of disability. In that sense, there has been an advance in correcting the idea that disability, understood from the biological medical model, is inherent to the person who «is disabled». For several years now, in the social model, it has been understood that living with a greater or lesser disability is the result of the interaction of socio-cultural barriers combined with personal impairments. The disability is no longer understood as the result of a personal physiological condition (of birth or acquired) but as the consequence of a series of concurrences that do not

allow its functioning, its social participation and its full development.

The change of paradigm about disability implied that it was no longer understood as an intrinsic condition of the person who suffers it and that it has to be corrected or adjusted, but as the result of social interactions with individual functioning. By transcending the rehabilitative biological medical model, disability could not be prevented solely from genetic design or *enhancement stricto sensu,* as it can be produced (is potentially produced) through attitudes, programmed experiences of exclusion, social interactions, architectural designs, and practices of invisibility of minorities.

Diseases, chronic conditions and disability are multi-causal realities, they do not have as their only origin a bad genetic design nor can they be avoided *a priori,* without considering the socio-cultural environments in which specific human beings are situated. They are not an atomized reality. The diagnosis, catalog, prioritization in care and treatment of the so-called «diseases» have changed according to the times, environments and socio-cultural contexts, will also change in future scenarios. Although the optimal functioning of a standard human body can be projected as an ideal of normality (at least as an average or socially accepted situation), it is an undeniable fact that situations of deficiency, malnutrition, social abandonment together with other synergies of comorbidity, aggravate ailments, produce diseases and even syndemics, which cannot be treated exclusively from the field we call medical.

What we are most interested in pointing out here is that illness cannot be transformed into health if it does not mediate processes of attention and that health fades, is transformed into illness, by processes of neglect at different levels and scales (family, community, national, cultural, environmental neglect, etcetera). The above indicates that societies produce pathologies and damages that, although avoidable, are gestated when the processes of inattention are potentialized among themselves with enough independence from the genetic conditions of particular individuals.

In accordance with the above, we consider that it is a mistake to seek as a goal the improvement and empowerment of human capacities, to improve the functionality of the body and the cognitive achievements, and with it to try to eradicate the disability from the beginning of human life. This is because disability, as we have seen, does not exist before the person's birth, nor does it even exist before the beginning of the socialization process, since it is produced by the interaction between the functioning and deficiencies with the specific socio-cultural environments. In this sense, the transhumanist argument about correcting the deficiencies and «errors» of human nature would lose its support, since, if we conceive of a person as a being with certain characteristics that acquire meaning from the social context, then there is no improvement that exists prior to birth. In addition to this, it should also be noted that behind transhumanist thinking there is a logic of domination of nature that, seeking to constantly overcome the limitations of the human being, is driven all the time towards an unreachable future generating an infinite pursuit between new improvements and emerging scenarios. Like a cat that chases its own tail, in this sense, *human enhancement* is driven all the time towards the future without achieving the ideal of happiness and fulfillment that is proposed in a stable way, since the technological restlessness is progressive (39).

In addition to the above, it is necessary to recall that as transhumanism sinks its roots in the modern project, it is biased by the blind belief in the possibilities of science and technology to improve the future of human beings (39), losing sight of the fact that this logic ends up in a dialectic of domination, as Max Horkheimer had noted: *For the sake of domination itself, domination is thus internalized. What is usually characterized as an end –the happiness of the individual, health and wealth– derives its significance exclusively from its possibility of becoming functional* (41, p. 116). In other words, as much as we want to have absolute control over nature, through its total dominion, in reality we end up surpassed by its power, because we become a simple experiment, a test tube.

The transhumanist proposal entails traps from which it is difficult to escape: desiring individual freedom (morphological freedom) while depending more and more on technology and the ideal of human functionality moves further and further away. To yearn for a happiness that is diluted by the internalization of the logic of power and the oblivion of what is truly human. It is overlooked that the project itself is immersed in a world where technology is as necessary as the air one breathes. Also, the very fact that the criteria of choice in genetic modification depend on a society, which is subject to a logic of progress and dominion over nature, causes it to choose emphatically based on parameters of productivity, utility and efficiency. Today the reactions against it represent only a minimal opposition given the speed with which science moves and the prevailing mercantilist ideas of society.

That is why we find it so necessary to highlight the contradictions and errors of the transhumanist argument; since, in its eagerness to control and manipulate the human body and mind from a merely functional criterion, it shows that its interest, besides instrumentalizing and objectifying the human being, reflects a notion of human existence as pure doing and effectiveness. We are sure that the human being is more than that; if we reduce the value of people based on their productive capacity to generate quantifiable results, then all those beings that do not enter into that possibility will be worth little, will be subordinated and even sacrificed (42).

Returning to the examples we gathered in the first section of this paper, let us recall the case of cycling (where, under the transhumanist argument, it would be easier and more efficient to produce high-performance athletes than doping athletes), to analyze the way it manifests the terror of not exercising control over the human body more than a real possibility of promoting human growth from a perspective that is not reduced to the mere biological potential of the body. As we had said, transhumanists tend not only to reduce but to mutilate human reality. The human being is not only a result, but a social and cultural being that is inserted in a

relational context with other very diverse human beings (that also interest, concern and even love). The transhumanist leaves aside diversity and interdependence in search of homogenizing and keeping under control one single global project. We consider this to be a mistake, not only because societies are diverse *per se* and possess plural objectives and possibilities, but because what really unites us as a species transcends the merely pragmatic and functional, the productive. On the other hand, it also transcends all differences without remaining in the merely corporal.

Now then, let us consider the issue of cognitive improvement. Let us put it to the test starting from a model of biological evolution where, from the beginning of life, human beings are subjected to long periods of dependence and fragility, leaving them exposed to disease and risking disability (43). Therefore, and in this sense, the key to success in our societies does not seem to lie in the independence, rational capacities or vigor of the body itself, but in interdependence and mutual care. As Kittay states:

> The very fact of human social organization is based on the fact that humans have been able to survive as the kind of dependent beings they are because they required shared care and social cooperation. Our rationality is less fundamental than our empathic and relational capacities that are basic to social organization (43, p. 78).

In clear opposition to Eva Kittay's approach –which we follow–, in the second example, the transhumanist eagerness to increase and improve the cognitive capacity of the human being seeks to suppress dependence on any type of effort and defends the renunciation of social support; since, her aspiration for autonomy based on intellectual improvement positions the individual as a winning project. In that sense, increasing the cognitive capacity aims to increase the independence of the human being, through the increase of the capacity of dominion of itself and its environment.

Finally, let us return to the third example about the functional and instrumental logic of transhumanists. The simple fact of attac-

king and questioning the case of the couple who wanted their daughter to be deaf shows that they only promote changes or modifications in favor of an enabling model of the human being. If we notice that the development model of current western capitalist societies also assumes the projection of bodily vigor, functionality and global health as part of the ideal of progress pursued through consumption, it is not difficult to find the link between capacitism and the commodification of bodies that lies beneath these approaches. Already Illich had denounced for years (1975) the medicalization of life assuring that the biotechnological parameters are also established by economic devices linked to the production of technoscientific dependencies and of a deep commodification of society (44). It could be said that the aspiration of global access to health would be equivalent to access to the distribution of goods in the biotechnology market. We would be facing a new bio-economic process of production of knowledge, needs, illnesses and disabilities to be corrected which, however, is presented to us as an exclusively biological project, under a somatic conception of illnesses, disabilities and sufferings. In other words, this decontextualized and reductionist conception of life, far from giving greater control to human beings, we believe, will only generate dependence on new emerging paradigms of disease and disability production. This makes emancipation impossible when, paradoxically, it is what the supporters of transhumanism were looking for as their initial project.

Conclusions

We have seen how the theorists who defend genetic modification techniques argue that by increasing our capabilities they will also avoid human pain and suffering. They do so, however, without distinguishing between pains, which is a physical symptom, and suffering, and the types of human suffering. They also overlook the fact

that a human life is inevitably exposed to disease and that vulnerability is a universal fact and yet they are not necessarily causes of suffering. Through authors such as Eva Kittay, Fiona Campbell, Barbara Arneil and Elizabeth Barnes we insist that human vulnerability and fragility can be seen as conditions of possibility, growth and fulfillment. Human limitations should not be seen in a tragic way or as a misfortune. From this starting point and based on these thinkers, we exposed a harsh critique of modernity, which connects with the well-known ideas of Max Horkheimer, to recover the critique of instrumental rationality and the consequent reification of the human being who conceives it only as a productive and functional entity. In that sense, the two questions we sought to answer were; first, whether the human being, in his eagerness to dominate and control human nature, ends up being dominated by technology himself. Secondly, if transhumanists have a biased vision of nature; since they reduce it to its utility and functionality, when in reality humanity is much more complex. We consider that transhumanism reduces it to the biological body excluding, at least, the political and socio-cultural. A key error in this sense, as we have seen, is that neither diseases are exclusively bodily nor is disability. Moreover, the excessive fear of diseases and fragility causes excessive medicalization and, end up with greater dependence when what they seek is an emancipation.

It is our view that the acceptance of vulnerability and conscious interdependence is the starting point of true liberation. Assuming what we truly are opens up the possibility of taking care of ourselves and establishing more humane political, social and cultural mechanisms, based on the logic of care and not on the logic of domination, consumption or bodily functionality and perfection. The human being is a relational being that lives thanks to complex networks of interdependence and flourishes in its interaction with others, in a vital dance that includes the search for autonomy, as well as the acceptance of dependency, intimacy and affective rela-

tionships with others, the consideration of the individual and the collective, which finds balance in the midst of complexity transcending its mere biological reality.

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Bibliographic notes

[1] The CRISPR-CAS9 method allows to modify the genotypes of a living being, based on the phenotypes that are desired to see manifested. It is a genetic tool capable of editing genes that determine certain traits (1).
[2] Some authors have delved into the subject of the domination of nature and the question of technique, see (10-12).
[3] It is our view that this position represents a step backwards from the progress that had been made in moving from the medical paradigm of rehabilitation to the social model of human rights. The progress meant that disability was no longer an intrinsic problem of the individual that must be solved, but rather an issue to be resolved from the social and political sphere where human abilities and functions interact with the social barriers produced by disability.
[4] We focus on these authors because they are the main exponents of the transhumanist movement and members of Humanity+. «The Transhumanist Declaration 'has been modified over the years by several organizations and individuals, although there is little record of the specific modifications and their respective authors. Nevertheless, the original 'Transhumanist Declaration' was crafted in 1998 by, in alphabetical order, Alexander Sasha Chislenko, Anders Sandberg, Arjen Kamphuis, Bernie Staring, Bill Fantegrossi, Darren Reynolds, David Pearce, Den Otter, Doug Bailey, Eugene Leitl, Gustavo Alves, Holger Wagner, Kathryn Aegis, Keith Elis, Lee Daniel Crocker, Max More, Mikhail Sverdlov, Natasha Vita-More, Nick Bostrom, Ralf Fletcher, Shane Spaulding, TO Morrow, Thom Quinn» (7, p. 3).
[5] Ignoring the psychosocial and environmental aspects that generate the disease.
[6] *Cf.* «Society establishes the means to categorize people and the fulfillment of attributes that are perceived as current and natural in the members of each of these categories. The social environment establishes the categories of people that can be found in it» (25, p. 11-12).
[7] *Cf.* «Kahane and Savulescu acknowledge that this account leaves open that what we think of as paradigm cases of disability might, in some circumstances, not count as disabilities. And that's because there might be circumstances in which

these features don't make people worse off (though they assert that most paradigm disabilities will be disabilities in their sense most of the time). But lots of things that we don't think of as disabilities have a negative impact on welfare. And any such feature, according to the welfarist account, should in fact count as a disability. Kahane and Savulescu are happy to accept the radically revisionary nature of their account» (26, p. 12).

[8] For Kittay, care is a moral capacity that serves as a source of human dignity.

[9] *Cf.* «It is a symptom that can accompany illness, an unpleasant sensory and emotional experience that is associated with an illness or injury and is valued as damage» (38, p. 10).

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